

Final Evaluation Report

Southeast Asian American Victims' of Torture Telemedicine Project

FUNDED BY

Technical Opportunities Program Grant # 116001063

Langeloth Foundation

Connecticut Health Foundation

TABLE OF CONTENTS

I. Overview of the Project.....	2
II. Evaluation Reports	
Outcome Study.....	5
<i>Submitted by Georgine Burke, Ph.D.</i>	
Methods.....	7
Results.....	10
Mental Health Outcomes.....	13
Discussion.....	18
Patient Satisfaction Evaluation.....	20
<i>Submitted by Ava Nepaul</i>	
Provider Satisfaction Evaluation.....	23
<i>Submitted by Ava Nepaul</i>	
Spoken Format Survey Results.....	25
Website Questionnaire Results.....	26
III. Appendices.....	28
Copies of data collection instruments	
Informed consent forms	
Privacy statements	

I. Project Overview

Nearly half of all Cambodian Americans live below the poverty level. Of the approximately 200,000 who survived torture and genocide in Cambodia, most continue to suffer from debilitating illnesses, lack strong English-language skills, are home-bound, and live far away from appropriate health care settings. This group is at great risk for becoming disabled at an early age or dying from treatable conditions. PTSD has been identified as a major factor for negative health outcomes and if treated can improve long term risks for diabetes and cardiovascular disease.

Khmer Health Advocates proposed to develop a telemedicine model that would significantly improve the quality of care refugees currently receive by providing them access to specialized consultation and treatment and to linguistically and culturally appropriate health education and prevention materials. In addition, the project will greatly contribute to the knowledge base of how to provide care for refugees by facilitating the collection, analysis and dissemination of data, and by providing a means to educate health care providers and support personnel. This model can be replicated in other refugee communities.

Changes to Original Plan

While the original plan was not significantly changed, the timetable for completion of services and products was significantly delayed by technology obstacles that included major equipment failure, network problems and changes in availability of partner resources. By the end of the time project period, the identified services and products had been developed but the timeframe allowed only for a preliminary evaluation of their effectiveness. [see list of products in attachments]

The most significant outcome for the project was the success of the outreach portion of the project which resulted in “spin offs” of the project to other organizations caring for traumatized, limited English speaking people. This is described in Khmer Health Advocates final report but a formal evaluation of this process was not part of the evaluation plan.

The delay in completion of elements of the project effected the dissemination plan which included the development of a handbook on telemedicine which would have been disseminated by the Southeast Asian American Resource Action Center (SEARAC). SEARAC has agreed to participate in the promotion of the telemedicine model if additional funding can be found for the completion of the handbook.

Lastly, a formal analysis of cost could not be completed because of a lack of time and resources caused by the delays described above as well as the rapidly changing cost of hardware, software and network fees for delivering high speed internet access.

Description of the Khmer Health Advocates Clinical Services for the Torture Treatment Program

Khmer Health Advocates has continuously operated a program for victims of torture since 1984. This program provides outreach to Cambodian communities in Connecticut and Western Massachusetts as well as psychiatric assessments, treatment and coordination of medical care.

KHA introduced the use of telemedicine to this program in February of 2004 but due to technical issues the telemedicine units were not fully functional until June of 2004. Since this date, the torture treatment program has functioned in the following manner:

1. The torture treatment team provides approximately 56 hours of professional service and 25 hour of paraprofessional service per week. Generally at least two members of the team are present at each session. Medical interpretation is provided by team members. The breakdown of staff time is as follows:

Name	Title	Direct Clinical Time	Support or administrative services
Richard A. Miller, M.D.	Medical Director	6 hours/week	4-6 hours
Mary Scully	Clinical Director	10 hours per week	10-12 hours
Theanvy Kuoch	Bi-lingual Therapist	10 hours per week	10-12 hours
Heang Tan	Community Health Worker	6hours per week	14-20 hours

- a. Richard A. Miller, M.D. 10
 - b. Mary Scully R.N., C.S. Clinical Director 20 hours /wk
 - c. Theanvy Kuoch, M.A.,L.P.C. bi-cultural Therapist 20 hrs/wk
 - d. Heang Tan, B.S, Community Health Worker 20 hours/wk
2. Care is provided for any Cambodian survivor of torture from any state however service areas are limited to offices in West Hartford, Ct, Danbury, CT and Amherst, Massachusetts.
 3. KHA does not maintain a waiting list but provides services on a triage basis. This means that patients with acute needs are seen first and those with chronic needs are seen as time permits. This system is understood by all participants in the program and after 21 years has not posed any problems.
 4. Referral to the KHA program can come from any source however, the vast majority of referrals have come directly from the Cambodian community and word of mouth.. It is estimated that fewer than 25% of referrals come from doctors, schools, social service agencies or law enforcement. KHA does not promote our services as we have continuously maintained a full roster of patients.

5. During the time period of June 1, 2004- September 30, 2005 included 115 patients from three states and 24 towns.
6. Patients receive services for the following in the order of initial reasons for contact
 - a. Assistance accessing health care and social services
 - b. Waivers for naturalization
 - c. Evaluations for establishing a disability claim
 - d. Legal reasons such as court referrals or Department of Children and Family referrals
 - e. Outreach for substance abuse programs
 - f. Treatment for mental health problems

A breakdown of time and number of services units is as follows:

Service	Ave. time	Minimum #	Total	max	Total
HSC,HTQ,SF12	1	2	2	2	2
MSE	0.5	2	1	6	3
Trauma History	1	2	2	6	6
Med history	1	1	1	3	3
Treatment plan	0.5	4	2	8	4
med review	0.25	6	1.5	24	6
total	4.25	17	9.5	49	24

average # of service hours
16.75 per patient

115 # of patients served in 2004

7. People can be admitted into the program as patients or clients. Patients are identified as those individuals who are seeking assessment of medical programs and or treatment for these problems. Clients are those individuals who seek only assistance with support services and who explicitly do not want an assessment or treatment. In addition to the 115 patients who are seeking medical or mental health services, KHA has an additional 35 people who occasional seek assistance for non health related issues such as family reunification, assistance with paperwork, school meetings etc.
8. Patients of the torture treatment program are able to control the ground rules for care. However there are certain expectations that are reviewed in the early part of the treatment process. These include the following

- a. all patients are expected to participate in an assessment process that includes the use of bi-lingual tools. These tools include the Khmer version of the Hopkins System Checklist, the Harvard Trauma Questionnaire and the SF-12. KHA. This assessment process is done approximately twice a year.
 - b. Participation in the program does not require compliance with a treatment plan. Patients are expected to notify Khmer Health Advocates if they choose to stop medication or if they do not want see us for treatment. It is made clear that they can return for services at any time without prejudice.
 - c. Khmer Health Advocates will periodically do outreach to patients who have not come for services to determine if they need help accessing services.
 - d. Patients agree that data from their assessments or from other parts of the medical record can be used for the purpose of gaining a better understanding of the health issues of Cambodian survivors and for quality assurance purposes. It is understood that names and identifiers are kept strictly confidential.
9. For the past 21 years, the KHA torture treatment program has been a free clinic and there are no fees for services, except for services contracted by an agency.
10. Patients in the KHA program have historically provided support services for other members of the community. These services might include providing food for families in need, helping with transportation or child care etc. This practice is called *Bravas dai knea* and is a culturally accepted form of give and take to maintain an active community.
11. During the period of the June 1st 2004 through Sept 31, 2005, patients could choose to see the KHA treatment team at the West Hartford, Connecticut office or from a satellite site in Danbury, Connecticut or Amherst Massachusetts. The team traveled to Danbury approximately once a month but did not travel to Amherst during this time period.

Report on Mental Health Outcomes

Southeast Asian American Victims' of Torture Telemedicine Project

Khmer Health Advocates, Inc.

November 15, 2005

Georgine Burke, PhD

Overview

This report describes the information gathered about clients of Khmer Health Advocates (KHA) during 2003-2005 who participated in a telemedicine-enhanced care program. The accompanying report from KHA report describes the program and its services in detail. In this section, we describe any changes in mental health assessment that may be associated with the telemedicine intervention.

The report is organized into four parts. Part one provides methodology for data collection and analysis and lists the indicators and other data that were collected for each participant. Part two describes the characteristics of program participants. Part three presents results from mental health assessment and examines changes in self-rated attitudes, feelings and diagnoses, comparing those who received a telemedicine-based service between 2003-2005 and those who did not. Section A presents data from all participants in the project; Section B describes the smaller group who had data collected at both baseline and at 12 month follow-up. Part Four is a discussion of the findings from the analysis.

I. Methods

A. Data Collection

Three instruments were used to determine the status of participants to the project. These are the Hopkins Symptom Checklist (HSC), a well-known symptom inventory, dating to the 1950s, that yields scores for dimensions of anxiety and depression of known validity. KHA has used a modified version of the HSC for more than 10 years as a diagnostic tool.¹ A second assessment instrument, the Harvard Trauma Questionnaire (HTQ), developed, revised and validated by the Harvard Program in Refugee Trauma of the Harvard School of Public Health,^{2,3} is a culturally specific instrument “designed for the assessment of trauma and torture related to mass violence and their sequelae. The HTQ is intended for use in both clinical and research settings with patient and community-based populations of diverse cultural backgrounds.” (HTQ manual, page 5). Like the HSC, the HTQ is a mainstay of the KHA diagnostic and therapy approach. Both assessment tools have been translated into Khmer.⁴ At the time participants were recruited to the project, each participant was administered the HSC, the HTQ and a third instrument, the SF-12, by face-to-face interview. A SF-12 was added specifically for this project in order to evaluate participant function. The SF-12[®] Health Survey, standard version, is a short-form of the SF-36, both developed by John Ware and others through sponsorship of the

¹ RF Mollica, G Wyshak, D de Marneffe, F Khuon and J Lavelle. Indochinese versions of the Hopkins Symptom Checklist-25: a screening instrument for the psychiatric care of refugees. *Am J Psychiatry* 1987; 144:497-500.

² Mollica RF, Caspi-Yavin Y, Lavelle J, et al. The Harvard Trauma Questionnaire (HTQ). Manual,

³ Mollica RF, Caspi-Yavin Y, Bollini P, Truong T, Tor S, Lavelle J. (1991) The Harvard Trauma Questionnaire: Validating a cross-cultural instrument for measuring torture, trauma and posttraumatic stress disorder in Indochinese refugees. *Jl of Nervous and Mental Disease*. 180: 110-115.

⁴ Mollica RF, Wyshak G, de Marneffe D, Khuon F, Lavelle J. (1987) Indochinese versions of the Hopkins Symptom Checklist-25: A screening instrument for the psychiatric care of refugees. *Am Jl Psychiatry*. 144: 497-500.

Medical Outcomes Trust.⁵ The SF-12 has been adapted for use in several cultures as an outcomes assessment tool measuring function and well-being. Although the SF-36 is a more generally-accepted instrument for small samples, at least one recent study comparing SF-12 and SF-36 with arthritis patients found general comparability. We selected the SF-12 for this project because of its brevity and availability of reference comparative data, due to its widespread use. Nevertheless, although the SF-12 has been used with Cambodians and a Khmer version is available, the cultural competence of the tool is questionable, especially for elderly and disabled respondents (eg. questions about playing golf). In order to compare the outcome scores from the KHA telemedicine group to other groups, the instrument would need to be scored with the weighted algorithms used by QualityMetric, Inc. Copies of the versions of each instrument used are attached to this report.

B. Data Analysis

Descriptive statistics were calculated for all measures, including participant characteristics, measures of participant contact and responses to the HSC, HTQ and SF-12. Scoring for each instrument was as described below:

	Scoring	Diagnostic Cutoffs
Hopkins Symptom Checklist HHSC)		
Depression score	Unweighted Sum of items 1-10	Sum >1.75
Anxiety score	Unweighted Sum of items 1-15	Sum >1.75
Harvard Trauma Questionnaire		
History of Trauma events	Unweighted Sum of 41 Trauma events	
PTSD score	Unweighted Sum of items 1-16	Sum > 2.5
Total Score	Unweighted Sum of items 1-40	
SF-12 Health Survey	Unweighted Sum of 12 items	N/A

Mean scores with 95% confidence intervals⁶ were calculated for each time period (baseline and 12 month follow-up). CIs are provided for reference purposes. Although the concept of “statistical significance” can be considered of limited usefulness in groups selected by convenience rather than through random sampling (and is declining in use in peer-reviewed journals), many people expect to see an alpha level when comparing groups. Comparisons were made between the telemedicine group and the group without telemedicine contact; those that reach statistical significance at 5% error or less are highlighted in **bold** text. Statistical significance can also be inferred from non-overlapping confidence intervals.

⁵ A revised version of the SF-12 has been developed and validated by Quality Metrics, Inc for proprietary distribution and use. KHA did not contract with Quality Metrics for the SF-12.

⁶ Confidence intervals (CI) estimate the likely range of means and proportions generated from sample populations (like the telemedicine participants) if they were to be generalized to a larger population (all Cambodian-Americans). A 95% CI estimates the “true” statistic with a probability 5% error. Confidence intervals will be broad for small samples. The generalizability of the KHA sample to a larger Cambodian American population is unknown.

Mean values for baseline vs. follow-up scores were evaluated with paired statistics, such as the paired t-test (for mean differences) or by comparing the average mean value (baseline+follow-up)/2 for each group.

Categorical measures, such as the frequency of a diagnosis in each group, are described as percentages with 95% CI. Comparisons between baseline and followup were calculated as percentage change from baseline to follow-up (follow-up-baseline)/baseline.

In all results, the group labeled “telemedicine” includes all clients of KHA who received any services through telemedicine. The “standard” group received standard KHA services (Table 5) through face-to-face contact in various settings (office, community site, client home).

As an indicator of internal validity, we compared scores among instruments for the project sample. The following tables display bivariate correlation coefficients (Pearson) among scores obtained at baseline and at 12-month follow-up.

Baseline Assessments (2003)

	HSC-anxiety	HSC-depression	HTQ-PTSD	HTQ-Total	SF-12
Hopkins Symptom Checklist (HSC)					
Anxiety Score	----				
Depression Score	0.45	----			
Harvard Trauma Questionnaire (HTQ)					
PTSD Score	0.50	0.54	---		
Total Score	0.47	0.51	---	---	
MOS SF-12[®] Health Survey (unweighted)	0.25	0.32	0.48	0.44	---

12-month follow-up (2004)

	HSC-anxiety	HSC-depression	HTQ-PTSD	HTQ-Total	SF-12
Hopkins Symptom Checklist (HSC)					
Anxiety Score	----				
Depression Score	0.79	----			
Harvard Trauma Questionnaire (HTQ)					
PTSD Score	0.83	0.89	---		
Total Score	0.80	0.86	---	---	
MOS SF-12[®] Health Survey (unweighted)	0.54	0.69	0.68	0.64	---

Correlations at baseline were highest between the HSC and the HTQ. Correlations with the SF-12 were somewhat lower for the HSC, but considerably higher for the HTQ. In 2004, correlations scores retained their relative ranking but increased dramatically. This increase could perhaps be explained by a learning or “test-taking” effect, but alternative explanations should be explored.

II. Results

A. Characteristics of participants

A total of 116 persons participated in the KHA telemedicine project. Among these, 63 (54%) had any contact with KHA caregivers through telemedicine. The average age of KHA clients was 48.5 years, with a range from 12 to 83 years. Seventy-five per cent were age 40 or above; 62% were female.

Table 1. Characteristics of participants, according to telemedicine use

Demographic characteristics	All participants (n=116)	Telemedicine (n=63)	Standard (n=53)
Age (years) (mean and 95% CI)	48.5 (45.9 – 51.1)	49.5 (45.9 – 52.9)	47.4 (43.5 – 51.3)
Female gender	72 (62%)	41 (65%)	31 (58.5%)

The majority of participants were just reaching adulthood at the time the Cambodian government fell to the Khmer Rouge in 1975.

B. Reported medical history

The most common medical problems were hypertension and chronic pain, each reported by approximately one-third (Table 2).

Table 2. Medical conditions reported by participants

Reported medical conditions	All participants (n=116)	Telemedicine (n=63)	Standard (n=53)
Hypertension	36 (31%)	23 (36.5%)	13 (25%)
Chronic Pain	37 (32%)	23 (36.5%)	24 (27%)
Diabetes	20 (17%)	12 (19%)	8 (15%)
Other (CVD, cancer, liver disease, COPD)	26 (23%)	15 (24%)	11 (21%)

By comparison, 32% of males and 31% in the US population between the ages of 45 and 54 were observed to have hypertension (NCHS: 1999-2000 NHANES). In contrast, 17% of participants report diabetes, about double the US rate of 7% among those ages 45-54.

According to assessment of the KHA staff (Table 3) , 43% suffered from symptoms of dementia that were characterized as serious (serious functional problems -- burns pots, driving accidents or near misses, can comply with treatment plan) or severe (should not live without supervision).

Table 3. KHA-Assessed Conditions

KHA-Assessed Conditions	All participants (n=116)	Telemedicine (n=63)	Standard (n=53)
Psychoses	6 (5%)	4 (6%)	2 (4%)
Substance abuse	19 (33%)	12 (19%)	7 (14%)
1. symptom relief			
2. regular abuse			
3. family/social problems			
4. end stage liver disease			
Dementia (serious functional problems, needs supervision)	49 (43%)	34 (54%)	15 (29%)
Trauma History* (mean total events) (CI)	18.5 (16.8-20.2)	19.4 (17.7-21.1)	17.3 (14.0-20.5)

*Harvard Trauma Questionnaire

In every category, persons receiving telemedicine therapy were more likely to be those with co-morbid conditions. Telemedicine recipients as a group were had more chronic and disabling conditions.

C. Contact history

The process for bringing participants into the study, conducting assessments and client follow-up are described in the KHA report. Table 4 displays the average number of contacts with KHA that each participant had in the year prior to implementation of the program (2003) and after 12 months of the intervention.

Table 4. Contacts with KHA, by telemedicine participation.

Contacts with KHA	All participants (n=116)	Telemedicine (n=63)	Standard (n=53)
New KHA client	48 (41%)	27 (43%)	21 (40%)
Contacts in 2003 (mean and 95% CI)	3.2 (1.8 – 4.6)	4.3 (2.6 – 6.0)	3.2 (1.8 – 4.6)
Contacts in 2004 (mean and 95% CI)	5.0 (3.9 – 6.2)	9.8 (7.8 – 11.7)	5.0 (3.9 – 6.2)

With the telemedicine project, KHA added 48 new clients. New clients were about evenly divided between telemedicine and standard contact. The average per client contact approximately doubled from 2003 to 2004 in the telemedicine group, a difference that was statistically significant.

Contacts were categorized as follows in Table 5.

Table 5. KHA Services

Type of Contact	Services
Assessment	Diagnostic testing, needs – basic and therapeutic
Treatment	Medications, individual or family therapy, other therapeutic approaches
Crisis	Access to care, financial support, intervention with police or state agencies
Support	Problem solving, information, education

As Table 6 indicates, nearly all clients received assessment in 2004, compared to 60% in 2003, an increase overall of 59%. The type of contact with the highest rate of increase between years (127%) was a contact initiated by client in crisis; however support contacts almost doubled (90%).

Table 6. Contacts with participants – Baseline and 12-month follow-up

Contact Type	Contact in 2003		Contact in 2004		% Change 2003 to 2004	% Change 2003-2004 telemedicine group
	#	%clients	#	% clients		
Assessment	70	60% (51-69%)	111	96% (90-98%)	+ 59%	+69%
Treatment	45	39% (30-48%)	67	58% (49-66%)	+49%	+63%
Crisis	11	9% (5-16%)	25	22% (15-30%)	+127%	+240%
Support	32	28% (20-36%)	61	53% (44-61%)	+90%	+91%

With the exception of Support services, a larger proportion of clients receiving services through telemedicine received services then did the standard group. This was most apparent for Crisis services, which doubled in the standard group but increased more than 200% in the telemedicine group.

III. Mental Health Assessment Outcomes

A. Outcomes for all participants

The following tables display scores at two time periods for two cross-sectional samples. They are all persons who were assessed at baseline and/or 12-month follow-up. Higher values indicate more negative ratings; therefore a decrease in mean score indicates improvement and conversely, an increase would indicate worsening symptoms.

Table 7. Assessment Tools – Scores at Baseline and 12-month follow-up

Baseline Scores Mean (95% CI)	n	Baseline	n	12-month follow-up (n=116)
HSC-anxiety	68	3.0 (2.9-3.2)	60	2.9 (2.7-3.1)
HSC-depression	68	2.9 (2.8-3.1)	60	2.7 (2.5-2.9)
HTQ-PTSD	60	3.0 (2.8-3.1)	59	3.0 (2.8-3.1)
HTQ-Total	61	3.1 (2.9-3.2)	59	3.0 (2.8-3.1)
SF-12	62	22.5 (21.5-23.5)	41	17.1 (16.1-18.1)

These scores indicate very little difference between participants who were assessed at baseline and those assessed at 12 months. SF-12 scores were better for the follow-up group. All but two participants at baseline scored in the range for depression. Although the percentage diagnosed with anxiety or depression was slightly lower at 12 months, , levels of depression and PTSD were high at both time periods.

Table 8. Assessment Tools – Diagnoses at Baseline and 12-month follow-up

Baseline Scores Mean (95% CI)	n	Baseline		n	12-month follow-up	
		#	% (CI)		#	% (CI)
HSC-anxiety	68	65	96 (88-98)	60	56	93 (84-97)
HSC-depression	68	66	97 (90-99)	60	56	93 (85-97)
HTQ-PTSD	60	46	77 (65-86)	59	45	76 (64-85)

A recent study by the RAND corporation documented a 62% rate of PTSD among Cambodians.⁷ Among these participants in the KHA telemedicine project, the rate was 76-77%.

These high rates of PTSD are reflected in the self-assessment scores of the SF-12 (Table 9)Table 8. Health Status Assessment

⁷ Marshall GN, Schell T, Elliott MN, Berthold SM, Chun CA. Mental Health of Cambodian Refugees 2 Decades After Resettlement in the United States. JAMA 2005 294: 571-579

SF-12 Questions	Response	% participants	
		Baseline	12 month follow-up
n of participants		62	44
1. In general, would you say your health is excellent, very good, good, fair, or poor	Fair/poor	87%	80%
Does your health limit your activities:			
2. --moving a table, pushing a vacuum, bowling, playing golf?	Limited a lot	58%	34%
3. --climbing several flights of stairs	Limited a lot	42%	30%
During the past 4 weeks:			
4. --have you accomplished less than you would like as a result of your physical health?	Yes	87%	86%
5. --were you limited in the kind of work or other regular activities you do as a result of your physical health?	Yes	87%	86%
6. --have you accomplished less than you would like to as a result of emotional problems, such as feeling depressed or anxious?	Yes	94%	93%
7. --did you not work or other regular activities as carefully as usual as a result of any emotional problems such as feeling depressed or anxious?	Yes	94%	91%
8. --how much did pain interfere with your normal work, including work outside the home and housework?	Quite a bit/extremely	59%	55%
9. --how much time have you felt calm and peaceful?	None/A little of the time	21%	26%
10. --did you have a lot of energy?	None/A little of the time	18%	26%
11. --how much of the time have you felt down?	All/Most of the time	63%	65%
12. --how much of the time has your physical health or emotional problems interfered with your social activities like visiting with friends, relatives, etc?	All/Most of the time	47%	40%

B. Outcomes among clients, according to telemedicine – paired comparisons

The 39 participants who completed assessments at both time periods were more likely to be female (69% vs. 58%), than the larger group of participants, but were of a similar age (mean 49 vs. 48 years). They had a history of more contacts in 2003 with KHA (5.5 vs. 2.9); 12 (32%) had no contacts in 2003, compared to 36 (51%) in the larger group. Comparing chronic disease rates, the paired group had higher rates of chronic pain (40% vs. 20%), but were less likely to have diabetes (74% vs. 87%) or hypertension (66% vs. 70%). The paired sample had a higher proportion of persons with dementia (89% vs. 79%). However, rates of alcohol and drugs use were similar (37% vs. 30%).

The following table displays information from only those participants in the paired group, comparing the mean scores (with 95% CI) for each of the assessment tools at both time periods, according to telemedicine use.

Table 10. Outcome scores from Assessment Tools – Baseline and 12-month follow-up by telemedicine

*Assessment Tool	Baseline Mean (CI)		12-month follow-up Mean (CI)	
	Telemedicine		Telemedicine	
Hopkins Symptom Checklist (HSC)	Yes	No	Yes	No
n	23	16	23	16
Anxiety	3.1 (2.8-3.4)	3.0 (2.7-3.3)	3.1 (2.8-3.4)	2.7 (2.3-3.1)
Depression	3.1 (2.9-3.3)	2.9 (2.6-3.2)	2.9 (2.7-3.2)	2.5 (2.1-2.9)
Depression (adjusted)			2.97	2.58
Harvard Trauma Questionnaire (HTQ)				
n	21	14	21	14
PTSD score	2.9 (2.6-3.2)	3.0 (2.6-3.4)	2.9 (2.7-3.1)	2.7 (2.3-3.1)
Total score	3.0 (2.7-3.3)	3.1 (2.7-3.5)	3.1 (2.8-3.3)	2.7 (2.4-3.1)
SF-12				
n	25	16	25	16
	22.2 (20.7-23.8)	22.3 (20.0-25.0)	17.9 (17.0-18.8)	15.7 (13.6-17.8)

*(unweighted sum)

Scores for both groups were similar at baseline. At follow-up, scores for anxiety, depression, PTSD, total HTQ and the SF-12 had improved in the standard group. These differences were statistically significant at follow-up for the SF-12 and the HSC depression score, as indicated by **bold** text. Scores in the telemedicine group tended to stay the same, but improved for the SF-12.

Because telemedicine participants had higher rates of chronic pain and dementia, we constructed multiple linear regression models to examine the HSC depression scores, while adjusting for these differences. Controlling for significant effects of chronic pain did not change the mean depression scores, which remained statistically significant between telemedicine and standard groups (Table 10).

Table 11. Diagnoses – Baseline and 12-month follow-up

Hopkins Symptom Checklist	n	Baseline Assessment (2003) % clients	12-month follow-up (2004) % clients
Anxiety	39	95% (83-99%)	95% (83-99%)
Depression	39	100% (91-100%)	95% (83-99%)
PTSD			

High rates of anxiety and depression in the paired group remained stable from baseline to follow-up. Table 11 shows changes within the telemedicine and standard groups. As these data indicate, the telemedicine group was less likely to show improvement in the proportion of participants with diagnoses of anxiety, depression and PTSD, though overall improvement rates were low.

Table 12. Diagnoses – Baseline and 12-month follow-up by telemedicine

Anxiety Change 2003-2004	n	Telemedicine	n	Standard
	23		16	
No change		87%		94%
Improved		4%		6%
Worsened		9%		0
Depression Change 2003-2004	n	Telemedicine	n	Standard
	23		16	
No change		100%		88.5%
Improved				12.5%

IV. Discussion

It is clear that the participants in the Cambodian telemedicine project suffer from morbidly high rates of mental and physical disorders. The RAND community-based study, conducted in Long Beach, California estimated rates of 62% PTSD and major depression of 51%. Since participants in the KHA project either sought help for their problems or were identified through case-finding, it is not surprising that rates of PTSD and depression were found to be much higher than the randomly selected Long Beach sample. With more than three quarters of the KHA telemedicine participants exhibiting Post Traumatic Stress Disorder, effects on daily activities, attitudes and mood are evident. 80% or more rated their health as “fair or poor”. Overwhelmingly, they reported being limited by their physical health and lacked the emotional resources to work, attend to daily activities or socialize with friends and family. In addition to emotional isolation, language, financial and transportation barriers limit their interactions with non-Cambodians, including the health care professionals who could potentially relieve some of their daily struggle. Therefore a major outcome of this project is the increase in the numbers of persons that were able to access KHA for help. Of the total of 116 persons studied, 48 had not been seen in the year prior to enrollment. The largest increase in service delivery was associated with crisis services and support services, activities that allowed participants to access Medicare or Medicaid, gave them information to help manage their diabetes, or connected them to other services. Telemedicine participants saw their contacts for crisis services increase by more than 200%. This increase in support contacts may have had some role in the improvements in daily function that were reported on the SF-12 at follow-up.

In general, levels of depression and PTSD did not decrease during the 12-month study period. Average scores for depression on the HSC decreased among Standard care participants, enough that diagnosis of depression changed for two persons. Among the telemedicine group, no changes in depression scores were clinically meaningful. Adjusting for higher chronic pain and trauma events in this group did not change this finding.

There are several limitations to this study that require caution in interpreting the findings. Foremost is sample size. Only 39 persons completed assessments at both time periods, a sample size yielding limited statistical power. This group was different from the larger group of participants. Second, participants were not randomized into telemedicine and standard groups and were most likely not comparable in areas both observed and those not measured. The ability to apply statistical controls on these differences through analysis is limited by the small sample.

Although the HSC and the HTQ have been validated with Cambodian populations, the SF-12 is still somewhat problematic. However, the level of agreement among these instruments was relatively high. At least two other measures that were proposed for this study were not applied.

Finally, these data were collected in the context of a demonstration project that involved numerous technical issues that impeded implementation. Telemedicine encounters did not actually begin until mid-year of 2004, more than 30 months into the project. This was mostly due to technical issues, but unanticipated problems at project sites (flooding, land use-related lawsuits) exacerbated the technical delays. Programmatic issues also negatively impacted the intervention. The TOPS funding required a 50% match, with limitations placed on activities from match funding such that clinical staff could not begin work until all technical issues were resolved. Project management structure did not include dedicated staff at remote sites, resulting in access issues for participants at these sites. It may be unrealistic to expect to see clinical improvement from an intervention that was fragmented and, at best, not fully realized.

Once the technical problems of the telemedicine services are resolved and management lessons learned from the pilot applied to the treatment model, these findings could inform the design of a larger, more rigorous study to assess outcomes.

KHA Patient Satisfaction Evaluation

Submitted by Ava Nepaul

Overview

A semi-structured interview of 30 Khmer Health Advocates Torture Treatment patient was conducted in Khmer by a single Community Health Worker (CHW) over a period of 3 weeks. This CHW was chosen to survey the patients as she is known to the Community but had only been employed by KHA for 2 months at the time of survey administration and was not directly involved in the care of the patients surveyed. The instrument [see Appendix] contained questions about use, cost, access, and acceptability of telemedicine as recommended by the Committee on Evaluating Clinical Applications of Telemedicine (Field, 1996). Aspects of the technical quality of the application were also examined. Subjects were first asked about their experience with in-person office visits and then about their experience with telemedicine.

C. Use

Twenty-four (80%) participants were female and the median age was 51 years with a range of 28 to 85 years. Twenty (67%) of the sample had in-person office visits in West Hartford during the past year while the remainder had in-person office visits in Danbury. Twenty-six (87%) had used telemedicine services at the Danbury location and 2 (7%) had used units in their homes during the past year. The majority of patients, 16 (53%), had seen a KHA caregiver using telemedicine 1 to 3 times during the past year.

D. Accessibility

Access is defined as the timely receipt of appropriate health care without undue burden to the care recipient (Field, 1996, p. 175). Twenty-four (80%) of respondents reported that it was “moderately” or “very” difficult to get to an office visits in West Hartford. Reasons for this included inability to read directions in English, discomfort asking family members or friends for assistance, inability to drive, and no access to a car. For 16 (53%) of subjects, a family member driving was the method to get to office appointments.

In contrast, seventeen (57%) reported that getting to a telemedicine location was “not at all” difficult. Those who reported getting to a telemedicine location as “moderately” or “very” difficult cited inability to drive, no car, or poor vision as reasons for the difficulty. Sixteen (53%) of those surveyed got to telemedicine appointments by driving themselves.

All survey respondents (100%) reported being able to obtain an office visit appointment within a week of when one was desired. Eighteen (60%) reported waiting less than 15 minutes for an office visit to start while the remaining 12 (40%) reported no wait. All 30 (100%) respondents stated they were able to obtain telemedicine appointments within a week of the time they desired. Upon arrival for a telemedicine appointment, 16 (53.3%) reported no waiting and 14 (46.7%) reported waiting less than 15 minutes.

E. Cost

Of the 20 clients who had office visits in West Hartford during the past year, 17 (85%) reported that getting to an office visit took greater than 1 hour and 13 (65%) reported missing time from work, household responsibilities, or school. Similarly, all 10 respondents who had office visits in Danbury reported that getting to an office visit took longer than 1 hour. The average transportation cost for an office visit was \$86.30 for the 27 (90%) of the total sample. For West Hartford patients, the average transportation cost was \$73.68; for Danbury patients it was \$93.00. Respondents stated that they relied on car services or family members to drive them to office visits. Eight (26.7%) reported family members missed time for work to take them to their office visits.

Twenty-nine (97%) of clients surveyed reported that getting to a telemedicine appointment took less than 15 minutes. No respondents (0%) reported transportation cost for a telemedicine visit, nor did any report missing time from responsibilities to get to a telemedicine visit.

F. Acceptability

Acceptability refers to satisfaction with the service. Respondents were asked about comfort, privacy, concern about the privacy of medical information,⁸ confidence in caregiver, overall satisfaction with the service, and the likelihood of using the service again.⁹

Twenty-nine (97%) of clients surveyed reported “always” feeling comfortable in the office. All 30 (100%) felt that they had enough privacy and were “very” confident that the caregiver was skilled enough to help. Twenty-eight (93%) were satisfied with office visits and the remainder was “moderately” satisfied. All 30 (100%) rated the quality of care received at office visits as “excellent”.

Of the 30 clients surveyed, 26 (87%) reported “always” feeling comfortable in the telemedicine location; 26 (87%) “always” felt that they had enough privacy. Twenty-six (87%) were “very” satisfied with their telemedicine visits and 25 (83%) rated the quality of care they received as “excellent”. When asked if they would recommend using the telemedicine unit to a friend or family member, 29 (97%) of those surveyed said “yes”; 1 response was not coded. When asked if they would have preferred to see a KHA caregiver in-person instead of via telemedicine, 14 (47%) had no preference; 10 (33%) preferred in-person; 5 (17%) did not prefer to see a provider in-person; 1 response was not coded.

Clients were also asked to give comments on what would make their in-person office visits and telemedicine visits better. Only 12 (40%) respondents made comments that reflected satisfaction with office visits and the psychiatrist. With regard to the telemedicine experience, clients commented:

- *Would prefer in person, but office too far;*

⁸ The probes written to address concern about the preservation of the privacy (4.10 and 5.10) were poorly worded and often required clarification. It assessed how concerned patients were about keeping their medical information private rather than how concerned they were that their personal medical information could be compromised by a particular service. As such, the data associated with these probes is not presented.

⁹ Probe 4.21 was poorly written and did not assess the likelihood of making another appointment for an office visit. Likewise, probe 5.22 should have been written: “How likely is it that you will make another telemedicine appointment?” Instead, it solicited responses about making another doctor’s appointment.

- *Like telemedicine;*
- *I think it is convenient for working people because it's located in Danbury and we are satisfied with seeing the doctor through computer;*
- *Would like to have telemedicine at home in case of an emergency.*

Technical quality of telemedicine application

Twenty-five (83%) of survey respondents reported “rarely” experiencing technical problems during the past year. Twenty-six (87%) “rarely” experienced poor picture or sound; and 24 (80%) reported that loss of picture and sound occurred “rarely”

Limitations

The instrument used was not adequately pilot-tested such that its reliability and validity could be established. This shortcoming is noticeable in areas that could not be assessed because of improperly constructed probes. The project would have benefited greatly from a low-cost, well-established, publicly available telemedicine evaluation tool.¹⁰

The sample was one of convenience and as such, subject to bias. The sample size of 30 individuals was very small. The instrument was created in English and translated to Khmer. The instrument was not back translated to ensure that meaning was consistent across translations. The instrument was administered in Khmer and responses were written in English so that the evaluator could analyze responses. Comments that were translated may have lost full meaning in this process.

G. Conclusion and Recommendations

This survey set out to accomplish what few telemedicine evaluations have not (Mair and Whitten, 2000) by comparing the telemedicine experience to the in-person office visit experience. Despite the limitations of the survey, the data generated demonstrates that telemedicine has greatly benefited KHA clients by making care more accessible and decreasing client transportation and time costs compared to office visits. Survey respondents were very satisfied with using telemedicine and found it not only convenient, but would recommend it to family and friends. The client experience of a reliable telemedicine system has no doubt contributed to the satisfaction of clients.

Future evaluations conducted by KHA will require more planning at the start of projects to ensure that evaluation is integrated into program design. This is dependent on adequate funding to retain skilled, independent evaluators with expertise in survey design for LEP populations and program evaluation.

H. References

- Field, M. J., ed. (1996). *Telemedicine: a guide to assessing telecommunications in health care*. Washington, DC: National Academy Press.
- Mair, F., Whitten, P. (2000). Systematic review of studies of patient satisfaction with telemedicine. *BMJ*, 320, 1517-20.

¹⁰ Although Elizabeth A. Krupinski, PhD of the University of Arizona kindly provided the evaluator with copies of evaluation instruments used by the Arizona Telemedicine Program in July 2005, these instruments did not address cost and accessibility at the levels KHA deemed sufficient.

KHA Providers Satisfaction Evaluation

Submitted by Ava Nepaul

A semi-structured interview of 7 KHA care providers was conducted between September 28-October 20, 2005 by a consultant. Two in-person and 5 telephone interviews were conducted using the instrument developed by the evaluator. [see appendix }. The instrument [see Appendix] contained questions about use, cost, access, and acceptability of telemedicine as recommended by the Committee on Evaluating Clinical Applications of Telemedicine (Field, 1996). Aspects of the technical quality of the application were also examined. Subjects were first asked about their experience with in-person office visits and then about their experience with telemedicine.

Interviews took an average of 20 minutes to complete. Subjects included 3 clinical care providers and 4 community health workers (CHWs). These individuals were asked about office visits and telemedicine use from June 1, 2004 to August 2005.

The providers surveyed saw client in-person at offices in the Amherst, Massachusetts Health Department, Danbury, the private physician's office in West Hartford, or the KHA office in West Hartford. Five of the 7 providers surveyed reported thinking that in-person office visits made a "very large" contribution to patient care. However, only the 2 CHWs who performed home visits felt that scheduling appointments was very convenient. For office-based staff, scheduling was more difficult and fraught with problems of "...distance, directions, timing, and entourage". This comment was made in reference to the problems patients have with reliable, timely transportation, following/remembering directions to provider offices, showing up on time, and arriving with other community members who are seeking services without a scheduled appointment. Most providers (71%) were "not at all" concerned about maintaining patient confidentiality. However, 2 were "a little" concerned because of patients who need to be seen with an interpreter who may be a relative. Another concern was with the "very small" Danbury office at there was a chance of conversations being overheard in other offices.

Overall, 71% providers were "very" satisfied with office visits; 1 "moderately", and 1 "a little". When asked what would make office visits better, providers wanted better, larger locations to see clients, more hours, and more staff to assist with overflow. A recurrent theme how difficult it was for clients to arrive for appointments on time due to transportation difficulties. These delays cut into available hours to see clients and left providers feeling very rushed and as if they had short-changed clients.

The telemedicine sites used by providers were located at the Amherst, Massachusetts Health Department, the KHA office in West Hartford, or home sites in Danbury. Providers received hands-on training from the initial users of the telemedicine setup and the KHA technical director. All felt the training was "very" helpful. One reported that the setup is a "scroll, click, and go" operation now. Overall, all providers were "moderately" (14%) or "very" (86%) comfortable using the telemedicine equipment.

From June 2004, technical difficulties with picture and sound occurred “rarely” according to 4 of 7 providers. The technical quality of the service was rated as “above average” by 4 of 7 respondents. The physical setup of the units was regarded as “average” by 3 providers. Two rated the setup “below average”; one because the unit was based in a shared office space, and another because of variable lighting conditions at the satellite that sometimes affect the client image. All providers reported that using telemedicine was “very” convenient and 71% reported it was “very” convenient to schedule telemedicine appointments. One CHW reported that scheduling a telemedicine appointment was “moderately” convenient because there were still issues with people getting transportation to the satellite site. With regard to the quality of communication with patients using telemedicine, only the English-speaking psychiatrist reported it as “average” owing to the use of an interpreter – all others felt the quality was “above average” or “excellent”. One provider had “a little” concern about patient confidentiality with regard to a home-based satellite unit that was sometimes used by other community members.

All providers (100%) thought telemedicine made a “very large” contribution to patient care. “We have greater access to patients. We have gone from seeing 65 clients per year to 120.” “There is less time lost to people getting lost and forgetting.” All providers (100%) would use telemedicine again and were “very” satisfied with the telemedicine application. “Telemedicine was extremely convenient. It made the impossible possible... people who needed help were able to get it right away.” The CHW in Amherst, Massachusetts remarked: “Telemedicine is very important for communities that are isolated like Cambodians in Western Massachusetts. Telemedicine helps people to keep in touch and that is very comforting to them.” Before telemedicine, this CHW would transport clients in a minivan from Massachusetts to West Hartford for services.

When asked what would make telemedicine better, providers expressed concerns about sustainability: “Right now we have learned a lot, but we need more funding to continue to work well because high tech costs a lot.” All providers reported the need for spaces that were solely dedicated to the telemedicine setup, particularly the receiver site based at the KHA office in West Hartford.

Results of the Ease of Use Survey for Spoken Format Data Collection

The *Ease of Use Survey for Spoken Format Data Collection* was administered to 39 individuals to evaluate the ease of use of the spoken format tools located on telemedicine units or via the web. Participants were clients from three organizations located in CT, IL and CA. Of the 39 respondents, 30 (76.9%) were female. The median age of the sample was 54 years with a range of 26 to 82 years. Participants were recruited on a voluntary basis and were showed how to access the spoken the format assessment tool and how to use the tool on their own. After participants completed the spoken format assessment, participants were asked the following questions in Khmer (Note: tabulations are in red):

PT ID #		Date	Data not entered in database	Time Started	Data not entered in database	RA ID#											
How long did pt work on survey before requesting help		A1 Data not entered in database	What did patient state as the reason, s/he could not continue without assistance		A2 Data not entered in database												
Place x in next column for each intervention necessary to help patient complete survey																	
Check all problems that apply B1___ Could not use touch screen. Unable to register answer with finger. 0 of 39 (0%) B2___ Needed to use mouse to register answer 1 of 39 (2.6%) B3___ Could not hear instructions 1 of 39 (2.6%) B4___ Not loud enough 0 of 39 (0%) B5___ Not clear enough 0 of 39 (0%) B6___ Could not understand wording of the question, needed clarification 16 of 39 (41.0%) B7___ Could not move to next page of questions 1 of 39 (2.6%) B8___ Afraid s/he would make a mistake 16 of 39 (41.0%) B9___ Did not like giving information to a computer Data not entered in database B10___ Other , explain						Of the 16 subjects who needed clarification, the following prompts were cited: <table border="1"> <thead> <tr> <th>Prompt</th> <th>No. problems</th> </tr> </thead> <tbody> <tr> <td>0</td> <td>1 (6.25%)</td> </tr> <tr> <td>1</td> <td>2 (12.5%)</td> </tr> <tr> <td>3</td> <td>2 (12.5%)</td> </tr> <tr> <td>4</td> <td>2 (12.5%)</td> </tr> </tbody> </table>		Prompt	No. problems	0	1 (6.25%)	1	2 (12.5%)	3	2 (12.5%)	4	2 (12.5%)
Prompt	No. problems																
0	1 (6.25%)																
1	2 (12.5%)																
3	2 (12.5%)																
4	2 (12.5%)																
Pt Satisfaction with Spoken format survey			Mean score= 6.34; lowest score = 5														
C1. What are your feeling about this survey			Disliked very much 1 2 3 4 5 6 7 Liked using this very much														
D. Comments <ul style="list-style-type: none"> • "this is helpful and I can understand the Khmer" • would rather have a person ask the question. The Khmer is "fancy" • Extremely enthusiastic. Like having the spoken Khmer and feels like she can have privacy and answer the questions at her own pace. Likes that she can go back and think about questions • "I will be able to do it if I practice a few more times" • It is very clear • problem with vision Sound is too soft. Has a hearing problem																	

Website Questionnaire Results (n=22)

The following are tabulations of the website questionnaire that were completed anonymously by 22 respondents across the United States. Participants were recruited verbally and/or via email. It is our hope to use these results to help improve KHA's current website.

II. User-Satisfaction	MEAN SCORE (% RESPONDENTS)				Response Types
		Negative	Neutral	Positive	
a. Did you find the information useful?	4.27	2 (4.5)	3 (9.1)	4.5 (86.4)	Not at all Very Useful 1 2 3 4 5
b. Did you like the website's appearance?	4.27	2 (4.5)	3 (13.6)	4.6 (81.8)	Not at all A lot 1 2 3 4 5
c. Overall, did you like using this website?	4.09	2 (4.5)	3 (13.6)	4.4 (81.8)	Not at all A lot 1 2 3 4 5
d. Would you recommend others to use this website?	4.55	2 (4.5)	3 (9.1)	4.8 (81.8)	Not at all Recommend to many 1 2 3 4 5

	MEAN SCORE (% RESPONDENTS)								
I. Ease of Use		Negative	Neutral	Positive	Response Types				
a. Did you think it was easy to find information?	3.86	0 (0)	3 (40.9)	4.5 (59.1)	Not at all 1	2	3	Very Easy 4	5
b. Did you think it was easy to go from one section to another?	4.09	2 (4.5)	3 (22.7)	4.6 (72.7)	Not at all 1	2	3	Very Easy 4	5
c. Did you think everything was clearly presented?	3.64	1.5 (9.1)	3 (31.8)	4.3 (59.1)	Not at all 1	2	3	Very Clear 4	5
e. Overall, did you think this website is easy to use?	4.0	2 (4.5)	3 (22.7)	4.3 (72.7)	Not at all 1	2	3	Very Easy 4	5
d. If not, what was unclear (Font, wording, etc)?	“Website transition not clear.” “I couldn’t differentiate what were links and what was just text.”								
f. Did you have any technical problems while using the website (i.e. a website page did not appear when you clicked on it.)	C. Yes 8 (36.4%)				No 14 (63.6%)				
	If yes, how many technical problems did you have? • 14 of 22 (63.6%) reported 1 technical problem • 8 of 22 (0%) reported 0 technical problems								

I. II. Recommendations
<p>Please provide us any recommendations you may have.</p> <ul style="list-style-type: none"> • “I wish we can have more Khmer text” • “Have both Khmer and English version” • “This website is good and easy to use. Lots of information, but this nothing new we like new stuff. Please update your website. Thx.” • “The website is off to a great start, and with some additional work has the potential to become a solid and informative site.” • “Need an update and more links with other health organization. Real story of Cambodians who wish to put their story in. Cambodian Alphabet spoken format. Identify how many Cambodians taking care their family health by using traditional healers and practice. Cambodian recipe.” • “Should update on current programs, national initiatives and efforts, and list out consultants on staff page.” • “There are grammatical errors in the true stories. Change colors to be more energetic, it is too red. Index, make more visible and accessible. The tabs should be larger for easier transitions. Need a website that is clear - quick to access for people who are in a hurry. Move logo into the center of the page - the head should be in the center. Title should be large and clear - do not place underneath logo. Rather, place on top.” • “Because of IRCO's work site, it is not suitable for clients to use computers.” • “Would like to see more pictures.” • “Update the upcoming events. They are actually past events now.”

